UC San Diego UC San Diego Previously Published Works

Title

Readability Assessment of Patient Education Materials on Uro-oncological Diseases Using Automated Measures

Permalink

https://escholarship.org/uc/item/69j4k3zg

Authors

Rodler, Severin Maruccia, Serena Abreu, Andre <u>et al.</u>

Publication Date

2024-07-01

DOI

10.1016/j.euf.2024.06.012

Copyright Information

This work is made available under the terms of a Creative Commons Attribution-NonCommercial-ShareAlike License, available at <u>https://creativecommons.org/licenses/by-nc-sa/4.0/</u>

Peer reviewed

ARTICLE IN PRESS

EUROPEAN UROLOGY FOCUS xxx (xxxx) xxx-xxx

available at www.sciencedirect.com journal homepage: www.europeanurology.com/eufocus



EUROPEAN

Education

Readability Assessment of Patient Education Materials on Uro-oncological Diseases Using Automated Measures

Severin Rodler^{*a,b,c*}, Serena Maruccia^{*d*}, Andre Abreu^{*a,b*}, Declan Murphy^{*e*}, David Canes^{*j*}, Stacy Loeb^{*f*}, Rena D. Malik^g, Aditya Bagrodia^{h,i}, Giovanni E. Cacciamani^{a,b,*}

^a USC Institute of Urology and Catherine and Joseph Aresty Department of Urology, Keck School of Medicine, University of Southern California, Los Angeles, CA, USA; ^b Artificial Intelligence Center at USC Urology, USC Institute of Urology, University of Southern California, Los Angeles, CA, USA; ^c Department of Urology, University Hospital of LMU Munich, Munich, Germany; ^d Department of Urology, ASST Santi Paolo e Carlo, San Paolo Hospital, Milano, Italy; ^e Sir Peter MacCallum Department of Oncology, Peter MacCallum Cancer Centre, Melbourne, Victoria, Australia; ^f Department of Urology and Population Health, New York University and Manhattan Veterans Affairs, New York, NY, USA; ^g Division of Urology, Long Beach VA Hospital in Long Beach, CA, USA; ^h Department of Urology, University of California-San Diego School of Medicine, La Jolla, CA, USA; ¹Department of Urology, University of Texas Southwestern Medical Center, Dallas, TX, USA; ^j Division of Urology, Lahey Hospital & Medical Center, Burlington, MA, USA

Article info

Article history: Accepted June 27, 2024

Associate Editor: Christian Gratzke

Kevwords: Patient education material Layperson Urology Health information dissemination

Abstract

Background and objective: Readability of patient education materials is of utmost importance to ensure understandability and dissemination of health care information in uro-oncology. We aimed to investigate the readability of the official patient education materials of the European Association of Urology (EAU) and American Urology Association (AUA).

Methods: Patient education materials for prostate, bladder, kidney, testicular, penile, and urethral cancers were retrieved from the respective organizations. Readability was assessed via the WebFX online tool for Flesch Kincaid Reading Ease Score (FRES) and for reading grade levels by Flesch Kincaid Grade Level (FKGL), Gunning Fog Score (GFS), Smog Index (SI), Coleman Liau Index (CLI), and Automated Readability Index (ARI). Layperson readability was defined as a FRES of >70 and with the other readability indexes <7 according to European Union recommendations. This study assessed only objective readability and no other metrics such as understandability.

Key findings and limitations: Most patient education materials failed to meet the recommended threshold for laypersons. The mean readability for EAU patient education material was as follows: FRES 50.9 (standard error [SE]: 3.0), and FKGL, GFS, SI, CLI, and ARI all with scores \geq 7. The mean readability for AUA patient material was as follows: FRES 64.0 (SE: 1.4), with all of FKGL, GFS, SI, and ARI scoring \geq 7 readability. Only 13 out of 70 (18.6%) patient education materials' paragraphs met the readability requirements. The mean readability for bladder cancer patient education materials was the lowest, with a FRES of 36.7 (SE: 4.1).

* Corresponding author. USC Institute of Urology Catherine and Ioseph Aresty Department of Urology, Keck School of Medicine, University of Southern California, Los Angeles, CA, USA. Tel. +1 626 491 1531

E-mail address: Giovanni.cacciamani@med.usc.edu (G.E. Cacciamani).

https://doi.org/10.1016/j.euf.2024.06.012

2405-4569/© 2024 European Association of Urology. Published by Elsevier B.V. All rights are reserved, including those for text and data mining, AI training, and similar technologies.

Conclusions and clinical implications: Patient education materials from leading urological associations reveal readability levels beyond the recommended thresholds for laypersons and may not be understood easily by patients. There is a future need for more patient-friendly reading materials.

Patient summary: This study checked whether health information about different cancers was easy to read. Most of it was too hard for patients to understand.

© 2024 European Association of Urology. Published by Elsevier B.V. All rights are reserved, including those for text and data mining, AI training, and similar technologies.

1. Introduction

Patients increasingly seek treatment information online [1] and use online information as a source of information prior to consulting a physician [2]. It is of upmost importance for international urological societies to provide high-quality patient education materials (PEMs) to prevent harm and give guidance, including pathways to seek professional urologist consultations. Both the patient office of the European Association of Urology (EAU) and the Urology Care Foundation of the American Urology Association (AUA) provide up-to-date PEMs across all conditions in urology. The process includes expert panels for the creation of scientific content and layperson input to ensure understandability of the content [3] based on the clinical guidelines.

Readability of PEMs is the key for dissemination and has to be adapted to a broad range of patients' literacy and knowledge. Appropriate readability levels are paramount to encourage patients to rely on information from validated sources since potentially untrustworthy sources might seem reliable due to higher focus on readability [4]. Readability of PEMs has revealed a correlation with understandability in vascular surgery PEMs [5], ENT PEMs [6], and urology questionnaires [7]. Further, low functional health literacy correlates with mortality [8].

Regulatory authorities aim to address this issue of readability of PEMs. The European Union (EU) Commission has issued guidelines to increase layperson understanding and involvement in clinical trials including minimum criteria for readability [9]. These criteria have been adapted to other fields, as demonstrated previously, for readability levels of urological abstracts and layperson summaries that revealed a clear lack of readability, which is currently not addressed by urological journals and might limit dissemination [10].

The aim of this study was to investigate the readability of the official PEMs of the EAU and AUA for cancer-related information.

2. Patients and methods

2.1. Patient education material selection

PEMs for uro-oncological conditions were retrieved from https://patients.uroweb.org for EAU PEMS and from https://www.urologyhealth. org for AUA PEMs. We selected the information for prostate cancer, bladder cancer, renal cell carcinoma, testicular cancer, penile cancer, and urethral cancer. For EAU PEMs, the patient leaflet was derived as a PDF for the respective cancer type. For AUA PEMs, text provided on the website was retrieved directly. The sections for a general explanation of the cancer type (called "about" section), causes, symptoms, diagnosis, treatment of localized disease (treatment localized), and treatment of metastatic disease (treatment metastatic) were extracted when available and the information was collected on October 10, 2023 (Supplementary Table 1).

2.2. Readability score and reading grade level assessment

Established readability scores and reading grade levels were assessed between October 11, 2023 and November 1, 2023, using a freeware readability score calculator tool (https://www.webfx.com) as described previously [10]. The Flesch Kincaid Reading Ease Score (FRES) was used to determine readability with a upper limit of 100 [11], while the Flesch Kincaid Grade Level (FKGL) [12], Gunning Fog Score (GFS) [13], Smog Index (SI) [14], Coleman Liau Index (CLI) [15], and Automated Readability Index (ARI) [16] were used to assess reading grade levels. Readability and reading grade levels thereby correlate inversely. A high FRES (\geq 70) and low FKGL, GFS, SI, CLI, and ARI reading grade levels (<7) indicate good readability, as reported previously [9,17]. The EU recommendation for layperson summaries were thereby followed as cutoffs [9]. Precise formulas for calculation of all scores are provided in Table 1.

All readability scores including the automated assessment tool have been used previously to assess health information [10,18].

The different sections of PEMs for each cancer type were copied and pasted from the master file into the readability score calculator separately to determine the readability for each section using the full-text function.

2.3. Statistical analysis

Continuous variables were presented as mean with standard error of the mean (SE).

The readability of PEMs from both the EAU and the AUA website was assessed independently. It is important to note that no comparative statistical analysis was conducted between the two sets of PEMs due to the use of different guidelines (EAU and AUA) by each organization in creating their materials.

Readability/reading grade level (abbreviation)	Formula
Flesch Kincaid Reading Ease Score	206.835 – $(1.015 \times \text{total words/total sentences})$ – $(84.6 \times \text{total syllables/total words})$
Flesch Kincaid Grade Level	$(0.39 \times \text{total words/total sentences}) + (11.8 \times \text{total syllables/total words}) - 15.59$
Gunning Fog Score	0.4 (total words/total sentences + (100 \times complex words/total words)
Smog Index	3+ √polysyllabic count
Coleman Liau Index	$(0.0588 \times average number of letters per 100 words) - (0.296 \times average number of sentences per 100 words) - 15.8$
Automated Readability Index	4.71 (characters/words) + 0.5 (words/ sentences) – 21.43

For the comprehensive analysis of the PEMs, the mean readability score was calculated for all the sections combined across all selected types of cancer and for each cancer. In addition, a separate analysis was performed for each specific section (including information about the disease, its causes, symptoms, diagnosis, and treatments for both localized and metastatic conditions) and for each type of cancer individually. This approach helped identify any variations in readability across different sections and cancer types. Data were reported combined and separately by cancer and by PEM section.

By using these two methods, we were able to comprehensively evaluate and compare the readability of the information across different sections (such as symptoms, treatment options, etc.) and also among the various types of cancer. This dual approach helped identify where readability varied, due to either the type of cancer being discussed or the specific section of information.

Minimal readability requirement was depicted in addition to readability scores for EAU and AUA patient material (red line): based on EU recommendations for layperson summaries in clinical trials [9], the reading level of an average 12-yr old and above was used as a threshold of appropriateness. Therefore, a FRES of \geq 70 and FKGL, GFS, SI, CLI, and ARI of <7 were considered the threshold for layperson readability [9,10,17].

3. Results

The mean FRES for both the EAU and the AUA PEMs was lower than the advised minimum readability standard of 70, indicating a level of difficulty not suitable for general public understanding. Furthermore, the average grade levels required to comprehend the PEMs from both the EAU and the AUA, as measured by FKGL, GFS, SI, and ARI readability scores, exceeded the levels recommended for materials intended for a lay audience, all \geq 7. This suggests that these materials may be too complex for the average reader, underscoring a need for simplification to enhance accessibility (Fig. 1).

When focusing on specific subdomains of PEMs, the mean FRES ranged from 38.2 (SE: 12.2) for causes in the EAU PEMs to 69.9 (SE: 2.1) for general information (about) provided in the AUA PEMs. Treatment for localized disease revealed the lowest mean FRES (57.9 [SE: 4.6]) within the different subdomains of AUA PEMs. In the reading grade level analysis, the layperson readability level recommendation of 7 is reached for general information (about) provided in the AUA PEMs for FKGL (6.4, SE: 0.4), SI (6.1, SE: 0.5), and ARI (6.1, SE: 0.6), and for symptoms in the AUA PEMs for SI (6.6, SE: 0.3). The mean of all other metrics did not meet the recommended threshold (see Fig. 2).

When analyzing specific cancer types, the recommended mean FRES was reached only for penile cancer (72.1, SE: 2.3) with corresponding low reading grade level (FKGL: 6.5 [SE: 0.5], GFS: 8.4 [SE: 0.5], SI: 6.3 [SE: 0.3], CLI: 10.5 [SE: 0.5], and ARI: 6.1 [SE: 0.7]), while the lowest mean FRES was observed for bladder cancer PEMs provided by the EAU (36.7, SE: 4.1) with corresponding high reading grade levels (FKGL: 13.2 [SE: 1.0], GFS: 15.7 [SE: 1.0], SI 11.4 [SE: 0.8], CLI: 15.5 [SE: 0.7], ARI: 13.deata9 [SE: 1.2]; see Fig. 3).

Details of each cancer type and each PEM section are outlined in Supplementary Figures 1–6.

4. Discussion

The development of PEMs holds significant value for patients and their caregivers, and it is essential to acknowledge the contributions of dedicated teams from the EAU and AUA. These groups dedicate considerable time and effort to translate complex medical guidelines into accessible information for patients, caregivers, and their families, ensuring that it can be understood easily and applied. In this study, we performed a quantitative readability assessment of PEMs and provided the first analysis of different sections of PEMs focusing on genitourinary cancers. Besides the correctness and high accuracy of the information provided, the average readability of PEMs did not reach the recommended thresholds for laypersons [9]. Better readability scores for general information, symptoms, and diagnosis, and worst readability scores for causes and treatment options were found. However, heterogeneity in readability levels was observed.

The EU has made substantial efforts to diminish barriers and democratize health care access with regard to education and readability of scientific and health care-related contents. As part of these efforts, recommendations for layperson summaries of clinical trials have been proposed, emphasizing the need to convey difficult to understand health information to an audience with potentially low health literacy in general or in a given topic [9]. These recommendations have been applied to the EAU and AUA patient information and are evaluated in this study. Almost all parts of uro-oncological PEMs have not reached the proposed readability level recommendations and might therefore impact the understandability of laypeople seeking information about urological cancers.

The assessment of urology PEMs represents an active research area, with heterogeneous results being dependent on the tool used and PEMs analyzed. About 10 yr ago, AUA PEMs have been reported to have had bad readability [19]. In 2010, the analysis of PEMs from the EAU patient office revealed better readability over time [20]. In the present study, despite an improvement in terms of readability compared with previous findings [19,20], we found that PEMs still has not reached the recommended thresholds [9] in readability scores, with high variability in readability being observed across the different cancer types. For EAU PEMs, bladder cancer reveals specifically low readability; however, patients with lower reading grade levels have higher bladder cancer incidence rates [21].

Notably, there is an association between lower socioeconomic status and worse survival among bladder cancer patients, further emphasizing the need to customize readability levels for this patient group to ensure effective communication and understanding of medical information [22].

The present study indicates the necessity for consistent and automated validated readability assessments prior to PEM publication using the available standardized scores and tools used to assess these.

Disparities arising through a lack of access to highquality care might be increased in underserved areas

ARTICLE IN PRESS

EUROPEAN UROLOGY FOCUS XXX (XXXX) XXX-XXX

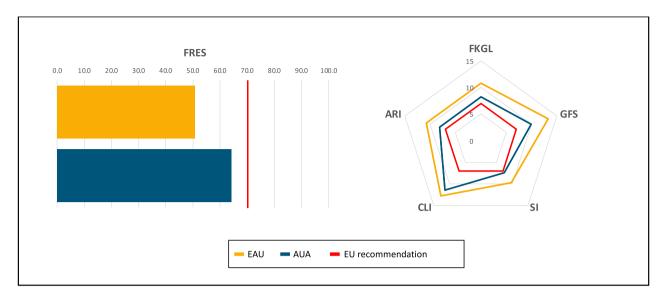


Fig. 1 – Cumulative readability of EAU und AUA patient education materials. Abbr.: Flesch Reading Ease Score (FRES), Flesch Kincaid Grade Level (FKGL), Gunning Fog Score (GFS), Smog Index (SI), Coleman Liau Index (CLI), Automated Readability Index (ARI), European Association of Urology (EAU), American Urology Association (AUA), European Union (EU).

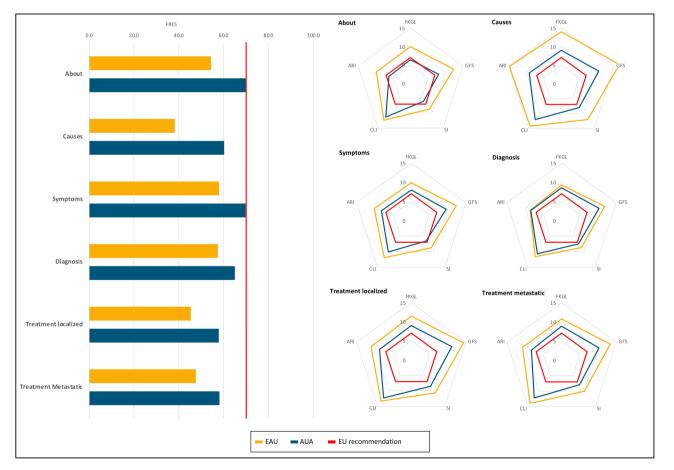


Fig. 2 – Cumulative readability of patient educational material for sections. Abbr.: Flesch Reading Ease Score (FRES), Flesch Kincaid Grade Level (FKGL), Gunning Fog Score (GFS), Smog Index (SI), Coleman Liau Index (CLI), Automated Readability Index (ARI), European Association of Urology (EAU), American Urology Association (AUA), European Union (EU).

4

ARTICLE IN PRESS

EUROPEAN UROLOGY FOCUS XXX (XXXX) XXX-XXX

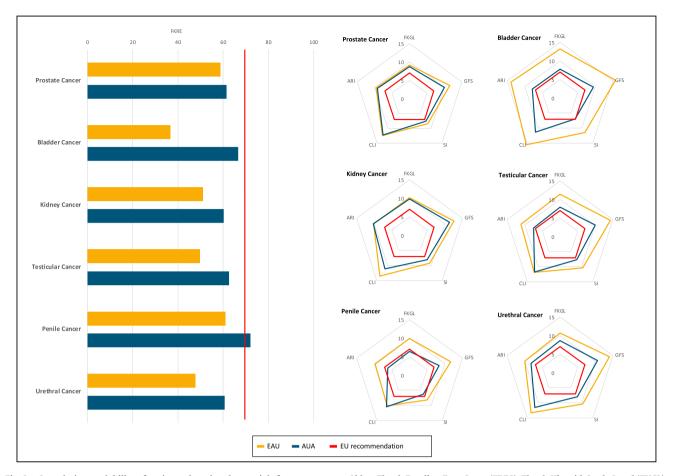


Fig. 3 – Cumulative readability of patient educational materials for cancer types. Abbr.: Flesch Reading Ease Score (FRES), Flesch Kincaid Grade Level (FKGL), Gunning Fog Score (GFS), Smog Index (SI), Coleman Liau Index (CLI), Automated Readability Index (ARI), European Association of Urology (EAU), American Urology Association (AUA), European Union (EU).

through barriers set by required educational levels to understand treatment recommendations of urological societies [23,24]. Patients with a lower education level and lower socioeconomic status experience disparities across all age categories and have inferior general health [25].

The process of updating PEMs, especially with the current advances in uro-oncology, is time consuming and in theory requires annual updates following guideline updates [26]. Besides expert teams conducting the background research and laypersons as well as patient advocates to control for understandability, using automated validated assessment tools (such as WebFX, as reported above) to check readability of PEMs prior to their release might be an important next step to standardize readability. Increasing the use of new tools in this process is of high importance as more advanced assessment of PEMs going beyond written text such as video or AI-based chatbots will be necessary in the future.

This study is limited to the analysis of readability, and direct conclusions to the understandability or dissemination of information might not always be drawn. However, the correlation between poor readability and understandability has been demonstrated as outlined [5]. No assessment including actual patients regarding the understandability of the analyzed patient information was

performed in this study, which remains a subject for further investigation. New technologies can be used to overcome health care barriers, as demonstrated during the COVID-19 pandemic, when telemedicine was adopted rapidly [27]. Similarly, new technologies, such as large language models, might be employed to address the readability issues of conventional PEMs and potentially enhance the understandability of the contents. In addition, this study evaluates only English-language PEMs and does not focus on PEMs in other languages. Further, PEMs would have to be a compromise to serve a variety of reading levels, as patients reveal high heterogeneity in educational backgrounds [28]. However, readability grants the backbone for objective assessment of PEMs [29], and automated assessment can easily be integrated prior to the release of new PEMs. Further investigations are ongoing on this regard and results are awaited.

5. Conclusions

This study observed that PEMs had worst readability than recommended for the general audience. The results suggest that there is room for enhancing the readability of PEMs, possibly by incorporating the use of validated automated assessment tools into the preparation process before the

Author contributions: Giovanni E. Cacciamani had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Rodler, Cacciamani. *Acquisition of data:* Rodler.

Analysis and interpretation of data: Rodler, Cacciamani.

Drafting of the manuscript: Rodler, Cacciamani.

Critical revision of the manuscript for important intellectual content: Maruccia, Abreu, Murphy, Loeb, Malik, Bagrodia, Canes.

Statistical analysis: Rodler.

Obtaining funding: Rodler.

Administrative, technical, or material support: Rodler, Cacciamani.

Supervision: Cacciamani.

Other: None.

Financial disclosures: Giovanni E. Cacciamani certifies that all conflicts of interest, including specific financial interests and relationships and affiliations relevant to the subject matter or materials discussed in the manuscript (eg, employment/affiliation, grants or funding, consultancies, honoraria, stock ownership or options, expert testimony, royalties, or patents filed, received, or pending), are the following: Andre Luis Abreu is a consultant for Koelis and Quibim, and speaker for EDAP. Severin Rodler receives consultancy fees from Merck, MSD, and Novartis, and has equity interest in Rocketlane Medical Ventures GmbH. Other authors do not have any competing interests.

Funding/Support and role of the sponsor: Severin Rodler is funded by Horst-Jürgen-Lühl-Foundation.

Acknowledgments: GPT4 was used to correct the grammar of the present manuscript. Severin Rodler and Giovanni E. Cacciamani validated the corrected version and take full responsibility of the manuscript in its final form.

Fig. 1. Cumulative readability of EAU und AUA patient education materials. ARI = Automated Readability Index; AUA = American Urology Association; CLI = Coleman Liau Index; EAU = European Association of Urology; EU = European Union; FKGL = Flesch Kincaid Grade Level; FRES = Flesch Reading Ease Score; GFS = Gunning Fog Score; SI = Smog Index.

Fig. 2. Cumulative readability of patient education material for sections. ARI = Automated Readability Index; AUA = American Urology Association; CLI = Coleman Liau Index; EAU = European Association of Urology; EU = European Union; FKGL = Flesch Kincaid Grade Level; FRES = Flesch Reading Ease Score; GFS = Gunning Fog Score; SI = Smog Index.

Fig. 3. Cumulative readability of patient educational materials for cancer types. ARI = Automated Readability Index; AUA = American Urology Association; CLI = Coleman Liau Index; EAU = European Association of Urology;

EU = European Union; FKGL = Flesch Kincaid Grade Level; FRES = Flesch Reading Ease Score; GFS = Gunning Fog Score; SI = Smog Index.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.euf.2024.06.012.

References

- Cacciamani GE et al.. Consulting "Dr. Google" for prostate cancer treatment options: a contemporary worldwide trend analysis. Eur Urol Oncol 2020;3:481–8.
- [2] National Cancer Institute. Health Information National Trends Survey (HINTS). https://hints-cancer-gov.libproxy1.usc.edu/viewquestions-topics/question-details.aspx?PK_Cycle=10&qid=688.
- [3] EAU Patient Office. Prostate cancer. https://patients.uroweb. org/cancers/prostate-cancer/.
- [4] Hirsch M et al.. Googling endometriosis: a systematic review of information available on the Internet. Am J Obstet Gynecol 2017;216:451–458.e1.
- [5] Scott BB et al.. Readability and understandability analysis of online materials related to abdominal aortic aneurysm repair. Vasc Endovasc Surg 2020;54:111–7.
- [6] Wong K et al.. Patient education materials assessment tool for laryngectomy health information. Head Neck 2017;39:2256–63.
- [7] Atalay HA et al.. Readability and understandability of andrology questionnaires. Turk J Urol 2019;45:171–6.
- [8] Bostock S, Steptoe A. Association between low functional health literacy and mortality in older adults: longitudinal cohort study. BMJ 2012;344:e1602.
- [9] European Commission. Good Lay Summary Practice. Guidance developed in cooperation with the Roadmap Initiative to Good Lay Summary Practice and adopted by the Clinical Trials Expert Group (CTEG, a working group of the European Commission representing Ethics Committees and National Competent Authorities (NCA)). Brussels, Belgium: European Commission; 2021.
- [10] Ganjavi C et al.. Clinical patient summaries not fit for purpose: a study in urology. Eur Urol Focus 2023;9:1068–71.
- [11] Flesch R. A new readability yardstick. J Appl Psychol 1948;32:221–33.
- [12] Kincaid P, et al. Derivation of new readability formulas (Automated Readability Index, Fog Count and Flesch Reading Ease Formula) for navy enlisted personnel. University of Central Florida; 1975.
- [13] Bogert J. In defense of the Fog Index. Bull Assoc Bus Commun 1985;48:9–12.
- [14] McLaughlin GH. SMOG grading—a new readability formula. J Reading 1969;12:639–46.
- [15] Coleman M, Liau TL. A computer readability formula designed for machine scoring. J Appl Psychol 1975;60:283–4.
- [16] Smith EA, Senter RJ. Automated readability index. AMRL TR 1967:1–14.
- [17] Shiely F, Daly A. Trial lay summaries were not fit for purpose. J Clin Epidemiol 2023;156:105–12.
- [18] Mac O et al.. Comparison of readability scores for written health information across formulas using automated vs manual measures. JAMA Netw Open 2022;5:e2246051.
- [19] Colaco M et al.. Readability assessment of online urology patient education materials. J Urol 2013;189:1048–52.
- [20] Betschart P et al.. Readability assessment of online patient education materials provided by the European Association of Urology. Int Urol Nephrol 2017;49:2111–7.
- [21] Densmore R, Hajizadeh M, Hu M. Trends in socio-economic inequalities in bladder cancer incidence in Canada: 1992–2010. Can J Public Health 2019;110:722–31.

- [22] Russell B et al.. Systematic review of the association between socioeconomic status and bladder cancer survival with hospital type, comorbidities, and treatment delay as mediators. BJUI Compass 2021;2:140–58.
- [23] Lillard Jr JW et al.. Racial disparities in Black men with prostate cancer: a literature review. Cancer 2022;128:3787–95.
- [24] Nyame YA et al.. Deconstructing, addressing, and eliminating racial and ethnic inequities in prostate cancer care. Eur Urol 2022;82:341–51.
- [25] Wu Y-T et al.. Education and wealth inequalities in healthy ageing in eight harmonised cohorts in the ATHLOS consortium: a population-based study. Lancet Public Health 2020;5: e386–94.
- [26] Ljungberg B et al.. European Association of Urology guidelines on renal cell carcinoma: the 2022 update. Eur Urol 2022;82:399–410.
- [27] Amparore D et al.. Patients' perspective on the use of telemedicine for outpatient urological visits: learning from the COVID-19 outbreak. Actas Urol Esp (Engl Ed) 2020;44:637–8.
- [28] Patki S et al.. A systematic review of patient race, ethnicity, socioeconomic status, and educational attainment in prostate cancer treatment randomised trials—is the evidence base applicable to the general patient population? Eur Urol Open Sci 2023;54:56–64.
- [29] Weis B. Health literacy: a manual for clinicians. Chicago, IL: American Medical Association, American Medical Foundation; 2003.